
**COMPARISON OF PARENTS' EVALUATION OF DEVELOPMENTAL
STATUS AND PROFESSIONAL ASSESSMENT FOR EARLY
DETECTION OF DEVELOPMENTAL DISORDERS IN INFANTS
BORN AT TERM WITH BIRTH ASPHYXIA AT TEMBISA HOSPITAL**

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Witwatersrand, in partial fulfilment of the requirements for the degree of Master of Science
in Medicine: Child Health and Neurodevelopment

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DECLARATION

I, Faustin Kabasele Mbuyi, declare that this research report is my own work and it has never been submitted before at the University of the Witwatersrand or any other institution. It is submitted to the University of Witwatersrand as a requirement for the degree of Master of Science in Medicine, Child Health and Neurodevelopment.



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Date 28/06/2015

DEDICATION

To my wife Rose Ngondo for your excellent support, help, and for giving me the space and time to study

To my children Merveille, Jemima and Bernice for being my motivation and accepting my distraction from your lives

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ABSTRACT

Background: Screening tools that rely on parents' information are effective tests used in child health to improve developmental outcomes. The PEDS combined questionnaires are designed for the overall developmental assessment of children aged 0-8 years and facilitate early intervention programs.

Aim: This study aimed to compare the PEDS combined and health professionals' developmental assessment as part of routine standard of care in eliciting neurodevelopment deviations in infants born at term with history of birth asphyxia at Tembisa Hospital, a public health care sector in South Africa.

Method: The present study is a descriptive cross sectional study. The developmental outcomes from the routine professional assessments were obtained from the review of medical records. Parents were asked to answer the PEDS combined questionnaires when their child was 6-12 months old to elicit developmental milestones in the infants. The comparative analysis was determined using the Kappa coefficient.

Results: The study sample included 34 infants and their parents (N=34). The PEDS combined questionnaires found that 7 (21%) infants had variable developmental concerns and unmet milestones, while the review of medical records revealed that 3 (9%) infants had development that was not age appropriate. The overall resulting kappa agreement between the PEDS combined and the routine professional assessment was moderate ($K=0.544$, 95% CI 0.170 to 0.917); with the PEDS combined more likely to identify developmental concerns and unmet milestones which included gross motor ($K=0.622$), fine motor ($K=0.785$), self-help ($K=0.532$), socio-emotional ($K<0.20$) and communication ($K<0.20$). On the contrary, the routine professional assessment was more likely to identify an infant with other/health concerns ($K<0.20$).

Conclusion: The PEDS combined screening test was more likely to identify more infants at risk of developmental problems. On the other hand, routine professional assessment, used in isolation, presented a risk of under-detection of developmental issues and could result in lack of referral of infants for early intervention. Socio-demographic characteristics did not influence the information provided by parents. If presented with standardised screening questionnaires, all parents can give accurate information about their child.

KEY WORDS: Infant; birth asphyxia; developmental screening; developmental disorder; PEDS; professional assessment; Tembisa hospital; South Africa.

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Table 1 List of abbreviations used in the study

Abbreviations	Description
PEDS: DM	Parents' Evaluation of Developmental Status: Developmental milestones
PEDS	Parents' Evaluation of Developmental Status
PEDS combined	Includes the Parents' Evaluation of Developmental Status and the Parents' Evaluation of Developmental Status: Developmental Milestones
ASQ	Age and Stage Questionnaire
AAP	American Academy of Paediatrics
EI	Early Intervention
GM	Gross motor
FN	Fine motor
CP	Cerebral palsy
SE	Socio-emotional
CI	Confidence interval
k	Kappa coefficient
PH	measure of hydrogen ion concentration
CT scan	Computerized Tomography scan
MRI	Magnetic resonance imaging
HIE 1	Mild Hypoxic ischemic encephalopathy
HIE 2	Moderate Hypoxic ischemic encephalopathy
HIE 3	Severe Hypoxic ischemic encephalopathy
CEO	Chief executive officer
HRC	High Risk Clinic
NICU	Neonatal intensive care unit

1 LITERATURE REVIEW

1.1 BACKGROUND

1.1.1 Birth asphyxia

1.1.1.1 Definition and outcomes

Birth asphyxia is defined by the World Health Organisation as the new-born's failure to initiate and sustain breathing after birth. It is also interpreted as impaired foetal gas exchange during labour (Motala, Davidson et al. 2010).

In developing countries the prevalence of moderate and severe birth asphyxia was estimated to be not less than 3% of live births. Whereas in developed countries, several surveys estimated the prevalence of birth asphyxia to be between 0.4% and 5.0% of live births (Shah 1991). Birth asphyxia occurred approximately in 1-6 per 1000 live, full term births (de Haan, Wyatt et al. 2006).

Globally, about 23% of neonatal deaths and 10% of all deaths in children less than five years of age were thought to occur as a result of birth asphyxia, and accounted for one million deaths each year worldwide (Halloran, McClure et al. 2009).

In the first perinatal care survey on intrapartum asphyxia conducted in South Africa between 2000- 2002 by the Medical Research Council Unit for Maternal and Infant Health Care Strategies, the resulting birth asphyxia and birth trauma were classified as the most common primary causes of perinatal deaths in rural hospitals (6.92/1000 births) and the second primary causes in urban hospitals (6.5/1000 births) (Velaphi and Pattinson 2007). This survey further showed that normal, term pregnancies resulted in birth asphyxia occurring in infants who otherwise would have been clinically well.

Survivors of birth asphyxia may suffer from hypoxic ischemic encephalopathy (HIE), leading to neurodevelopment disorders and subsequent motor, sensory motor, cognitive, learning and behavioural disorders (Halloran, McClure et al. 2009). Almost half of term newborns who were asphyxiated at birth developed signs of HIE in the early days of life. Newborns with HIE 1 did not have a high risk of sequelae, and on the other hand, about half of those with HIE 2 had the diagnosis of cerebral palsy. The remaining newborns

were developmentally normal at 18 months follow up (Lindström, Lagerroos et al. 2006). The severity of HIE appeared to be the single best predictor of outcome in birth asphyxia. The HIE 3 carried a 75% risk of death and a 100% risk of neurodevelopment problems in survivors (Thilo and Rosenberg 2012).

Approximately 150 million children, making 5-10% of the general paediatric population, suffered from certain kind of disabilities, and most of them lived in the low- and middle-income communities. Further, the larger number of these children and their parents suffered the associated stigmatization, which leads to a marginalized life and the concomitant family burden (Maulik and Darmstadt 2007, Aly, Taj et al. 2010).

1.1.1.2 Birth asphyxia consensus

Over the years, there have been various efforts to reach consensus on what should be considered the primary diagnosis for birth asphyxia. The commonly-used markers in the consensus on birth asphyxia are Apgar scores (≤ 6 at 5 min), umbilical cord blood gas (pH < 7.0 or base deficit > 12 mmol/L), HIE, the clinical signs of foetal distress, including the passage of meconium in the uterus, abnormal foetal heart rate patterns (> 160 beats/min or < 110 beats/min) and delay in spontaneous respiration, dysfunction of systems other than the brain, electroencephalography patterns and findings on cerebral imaging (Pin, Eldridge et al. 2009).

1.1.2 Screening for developmental and behavioural disorders

The American Academy of Paediatrics (AAP) recommends the use of surveillance and screening processes for the identification of children who would require developmental assessment and evaluation. Developmental screening is a proactive process that involves assessing every child to identify those at higher risk of significant and unsuspected clinical deviations from normal development. It is an assessment that uses validated screening tools. Whilst the developmental surveillance is a continuous and flexible process used by most primary health care professionals to observe and monitor the developmental trajectory of a child during health care services. The surveillance process also includes identifying and attending to parental concerns, and sharing opinions and information with other health professionals (Aly, Taj et al. 2010).

Many screening tests and technologies are designed for determining and predicting long-term neurological and behavioural outcomes. Such technologies include the CT scan of the brain, the MRI of the brain, the monitoring of brain function, the Doppler of the middle cerebral artery and cranial ultrasound. Specific developmental screening modalities are parts of professional assessment and are used by physiotherapists, occupational therapists, speech and audio therapists, social workers, psychologists, and paediatricians. However, for many paediatric units in South Africa and other developing countries, these modalities and technologies are not always available (Mwakyusa, Manji et al. 2009).

Most children with developmental disabilities and mental health problems were not identified, and less than half of those with developmental delays were identified before starting school (Glascoe 2000). This showed that the greater percentage of children was overlooked during screening or surveillance, or because of the lack of screening. These missed opportunities lead to the disability of the child who suffers from developmental delay and affect the whole family (Aly, Taj et al. 2010). Early intervention is needed to improve the outcomes of these disabled children (Glascoe 2000).

Carefully eliciting parental concerns and observations about the child's development are valuable surveillance and screening tools and are readily available (Aly, Taj et al. 2010).

In 2008 a study was conducted on intellectual disability in the South African population using the Ten Questions questionnaire for the screening of 6,692 children (2-9 years old) from 3,405 households in the Bushbuckridge district in rural Limpopo (South Africa). This study identified the need to use, upgrade and manage parents' knowledge of and concern for the health problems in their children. The results showed that 4.3% of children had at least one of five disabilities, which included intellectual disability, epilepsy (not febrile fits), movement, and visual and hearing disorders. Of these, intellectual disability was the most prevalent at 3.6% (Kromberg, Zwane et al. 2008). These data point to the necessity for using screening tools and for involving parents or guardians in the evaluation of clinically significant developmental behavioural problems.

1.1.3 Screening tools

Although there were many different screening tools available, this discussion was confined to the Parents' Evaluation of Developmental Status (PEDS) combined.

1.1.3.1 Parent-administered questionnaire: (PEDS) combined

Parents are readily available sources of clinical information. A parent-administered questionnaire is a dialogue with parents, and gives them the opportunity to bring up every developmental concerns they may have regarding their child. It involves asking parents to complete a questionnaire, and it has the advantage of being brief and simple to use. Parents with poor literacy may be offered assistance with completing out the questionnaire or by administering the screening as an oral interview. Researches have shown that parents' involvement in the developmental screening improves its accuracy because they are good at observing their children's behaviour and development, and know their child best (Glascoe 1999, Centre for Community Child Health 2011).

PEDS combined includes the PEDS and the PEDS: Developmental milestones (DM) questionnaires and it has acceptable psychometric properties as a developmental screening tool. The PEDS combined offers a bigger developmental picture, focuses the visit on both the child's and parent's needs, enhances the teachable moment and helps clinicians provide an optimal response. It elicits and addresses parental concerns, and has been developed to help health-care practitioners provide early developmental assessment and make skilled observations for early interventions focusing on children up to eight years of age. This age range includes the critical period for brain growth and development (Glascoe 2000).

The PEDS combined can be used in any setting and has minimal costs. This screening test can be filled out in the waiting room, taken home to prepare for the next follow up visits, or performed as an interview or telephonically when families do not make regular clinic visits. Health professionals such as doctors and nurses, and other professionals in childcare centres, preschools, kindergartens, and schools can use the PEDS combined (Glascoe 1999, Centre for Community Child Health 2011).

1.1.3.2 Professional assessment

Health professionals use standardized, validated developmental screening tools to identify the children at high risk of clinical deviations from normality. Different developmental domains including gross motor (GM), fine motor (FM), language and social-emotional (SE) development, as well as adaptive skills are addressed by these screening tools. The professional assessment therefore provides a more comprehensive, proactive and intensive diagnosis and evaluation to identify children with developmental deviations. These assessment tools are expensive, time consuming, and require training and high level expertise from the assessors (Aly, Taj et al. 2010).

Many children in developing countries may never be assessed developmentally in the first three years of early childhood period, because of the inexistence of routine newborn or childhood professional screening (Aly, Taj et al. 2010).

In South Africa, the diagnosis of hearing loss was made after 2 years of age on average, as a result of lack of screening programmes in infants. The implementation of interventions took place after 8 months delay following the diagnosis. Approximately 5 500 children with incapacitating hearing loss were missed annually. At the time of the study, the identification of these infants was primarily passive, relaying on parents' concerns about their infants' speech development, observed behaviour or complications of otitis media. Paediatricians and speech- audio therapists relied on their own initiatives for the screening processes (Swanepoel 2009).

The professional assessment involves professionals from a variety of health disciplines. The multidisciplinary team may include paediatricians, medical officers, physiotherapists, occupational therapists, audio and speech therapists, psychologists, and social workers. Specific benefits of the professional assessment include early diagnosis and interventions, improved decision making, continuous professional training of the team members, protection and advocacy for children, better outcomes, and enhanced efficiency (Jones, Worthington et al. 1998).

1.1.4 Comparison of PEDS combined and professional assessment

Glascoe stated that “if systematically elicited, parents' concerns approach the standards for screening tests and can be used to make reasonably accurate referral decisions” (Glascoe 1997). Significant parental concerns about the development of their children offer far more advantages for the screening test (Theeranate and Chuengchitraks 2005). Chen and associates further stated that parental concerns have the same accuracy as quality screening tests (Chen, Lee et al. 2004).

A hospital based study was conducted by Chen et al. (2004) to evaluate the comparison between parents' developmental concerns and professional developmental assessment during childhood. The study found that parental concerns about speech, GM, FM, and behavioural development had a high sensitivity toward the same developmental domain diagnosis (77-89%). However, cognitive concerns had a low sensitivity (15-36%). The study also revealed that speech, GM, and FM developmental delays had higher positive predictive values (55-77%). On the other hand, cognitive or behavioural delays had lower positive predictive values (25-33%). These findings pointed to the fact that the role parents play in detecting motor, behavioural and speech developmental delay in children is important. Parents' concerns about the development of their children are important in the decision for referral to have further assessment.

A study conducted in the Private health care sector in South Africa compared screening questionnaires based on parents' information to the subjective assessment by paediatricians. An estimated 40% and 42% of infants were found to have developmental concerns following the administration of the Age and Stage Questionnaire (ASQ) and the PEDS combined and the paediatricians' subjective assessment identified only 6% of the cohort. The study showed an agreement between the ASQ and PEDS combined in identifying children with developmental concerns. Paediatricians identified significantly fewer infants and showed statistically significant poor agreement with both questionnaires (Silva 2010).

1.1.5 Tembisa hospital

Tembisa hospital is located in the Tembisa Township. The community is served by primary health-care centres and Tembisa Hospital, the only public hospital in the area. The Tembisa Hospital has approximately 850 beds and all departments are supervised by consultants. This is where approximately 1200 births are registered monthly, and on average 10 newborns with birth asphyxia are admitted to the paediatric intensive care unit every month and followed at the neurodevelopmental clinic after discharge from the hospital.

Tembisa area is one of the largest townships in the East Rand region of Gauteng in South Africa. It has a catchment area of 32.44 km² and a total population of approximately 511655 (Geonames 2011, Statistics 2014). As in many other South African townships, Tembisa is constantly developing and growing, characterised by unemployment, low- and middle- income families, and scarce natural resources.

1.1.6 Justification for the study

The PEDS combined and professional screenings tests are both designed for early detection developmental disorders in at risk children. In the South African public health setting no studies have been undertaken to compare the agreement between the PEDS combined and routine professional assessments in screening high risk children. Therefore more research is needed to improve the relevant knowledge and add to the growing body of the literature on parent-administered questionnaires and professional assessment for children developmental screening.

The above studies have proved that both parent-administered questionnaires and professional assessment can be used as screening tools to evaluate children's developmental problems. Early identification of developmental delays facilitates early intervention, and provides long term benefits to the child, the whole family and society. Involving parents in the screening process increases its accuracy, is justified by the minimal cost, and provides a family- centered approach to the child health care.

1.1.7 Aim

The current study aimed to compare the PEDS combined and the routine health professionals 'developmental assessment in eliciting neurodevelopment delays in infants born at term with a history of birth asphyxia at a public health care sector in South Africa.

2 SUBJECTS AND METHODS

2.1 OBJECTIVES

The objectives of the present study were:

1. To describe the demography of parents using the PEDS combined
2. To evaluate the PEDS combined as screening tool in birth asphyxiated infants
3. To compare the PEDS combined and the routine health professional assessment in detecting developmental delays

2.2 STUDY DESIGN

The present study was a descriptive cross sectional study.

2.3 STUDY AREA

The study site was the high risk and neurodevelopment clinic (HRC) at Tembisa hospital. The clinic was held on Tuesday and Friday every week, except on holidays. The clinic was run by a paediatrician assisted by a medical officer. There were also allied health workers including physiotherapists, occupational therapists, audio and speech therapists, social workers, psychologists and skilled nursing staff.

2.4 STUDY POPULATION

The study population comprised infants with a history of birth asphyxia and the parents. Parents were invited to participate in the study and to answer the PEDS combined questionnaire when their infant was 6-12 months old. This would allow health workers to

understand parents' perception of their infant's developmental delay. The study was conducted between October 2013 and January 2014.

2.5 INCLUSION AND EXCLUSION CRITERIA

2.5.1 Inclusion criteria

Inclusion criteria included all infants born at term with a history of birth asphyxia, who were admitted to Tembisa Hospital NICU within 24 hours of birth, and who were seen at HRC at 6-12 months of age. The consensus on the diagnosis of birth asphyxia used at Tembisa Hospital was considered for the current study. This included consideration of essential markers such as impaired level of consciousness, decreased muscle tone, decreased reflexes like the Moro and Suckling reflex, and the presence or absence of seizures; impaired blood gas with base deficit > 12 and PH < 7.0 as supportive marker; and APGAR score < 7 at five minutes as an additional but inconsistent marker. Overall, this consensus on birth asphyxia was in accordance with the Sarnat classification of hypoxic ischemic encephalopathy (HIE) as mild HIE (I), moderate HIE (II) and severe HIE (III) (Lindström, Lagerroos et al. 2006).

Term newborns were defined by a gestational age of completed 37-42 weeks or birth weight ≥ 2500 g. The parents' ability to speak English was required so that they could answer the PEDS combined questionnaire and participate in the study.

2.5.2 Exclusion criteria

Infants with obvious congenital malformations or a history of central nervous system infection were excluded from the study. Parents who declined to participate in the study were excluded.

2.6 PROFESSIONAL ASSESSMENT OUTCOMES

Developmental outcomes were based on clinical assessment by doctors in the HRC. These included the cognitive, GM, FM, language, behaviour and SE, as well as adaptive skills. No formal neurodevelopmental assessment was done during the clinic visits at the HRC at Tembisa hospital.

2.7 DATA COLLECTION

The study population was identified from the clinical records of babies who had been admitted to the neonatal ICU at Tembisa hospital with a history of birth asphyxia and who were attending the HRC. All parents of identified children were given a talk and an information leaflet in the waiting room to introduce the researcher and the purpose of the study on every day that the clinic was running. The parents were encouraged to clarify any question in the PEDS combined questionnaire with the researcher. Parents were told that the participation in the study was completely voluntary and that non participation or withdrawal would not compromise the treatment they received. Thereafter the questionnaire was handed over to the consenting parents and was collected at the time of consultation. Parents with poor literacy were offered assistance with filling out the questionnaire or by performing the screen as an oral interview.

The major concerns of parents were categorized by various developmental domains which include expressive language, receptive language, GM, FM, self-help, cognitive development, hearing, and vision, SE, and behavioural.

Parents at the HRC knew about their children's birth history. It was a routine at Tembisa hospital to counsel mothers on their at risk infants birth diagnosis before discharge from hospital. However, counselling was offered to parents who did not know that their child had birth asphyxia.

Children identified at risk of developmental delay were referred appropriately for further professional assessments or screenings. Their parents were offered counselling, with emphasis on the necessity for professional assessment and referral for therapeutic interventions. The developmental assessment outcomes from health professionals was retrieved from the child's clinical record and captured in a data capture sheet. These assessments were categorized by various developmental domains including expressive language, receptive language, GM, FM, self-help, cognitive development, hearing, and vision, SE, and behavioural or no developmental deviation. The health professional outcomes were compared against PEDS combined scores for each child in the study.

2.8 DATA COLLECTION TOOLS

Data collection tools included a socio-demographic questionnaire for the parents and the PEDS combined questionnaire.

2.8.1 Demographic questionnaire

The demographic questionnaire included variables such as age, gender, income, occupation, literacy, level of education, and relationship to the child.

2.8.2 PEDS combined

The PEDS combined involves two sets of questionnaires, the PEDS and the PEDS: DM. The PEDS comprises 10 questions, which are addressed to parents and the PEDS: DM includes six to eight items focusing on children's skills in each developmental domain: FM, GM, expressive or receptive language, self-help, and SE factors. For older children, preschool and school skills are included. These questionnaires are standardized and validated screening tests designed to elicit, address and score parents' concerns about developmental deviations. The PEDS combined has been developed to help health-care practitioners provide early developmental assessment and make skilled observations for early interventions focusing on children from birth to eight years of age. It has a sensitivity between 74% and 79%, and a specificity between 70% and 80% across age groups. Parents of children with developmental delay should have an educational level of standard 5 or more to answer the screening questionnaires. In cases of poor literacy, the researcher explained the questionnaire and helped parents who had difficulties with reading and writing (Glascoe 2000). The questions to parents required approximately five minutes to complete and it took one or two minutes to score the questionnaire to get the PEDS combined score. The PEDS combined score was classified as low, moderate and high risk of developmental and behavioural problems. The PEDS combined scores helped identify when to refer or provide further screening, counsel, reassure or monitor development, as well as academic progress (Glascoe 2011).

2.9 STATISTICS

2.9.1 Study analysis

As a preliminary analysis, a description of the baseline data was summarised using frequencies or percentages for categorical data; and means for continuous data. On the analytical level, the Kappa inter rater agreement test was used for the comparison of PEDS combined scores with professional assessment outcomes.

2.9.2 Sample size calculation

On average 10 neonates with birth asphyxia were admitted to the NICU every month and followed at the HRC after discharge from hospital. Between October 2013 and January 2014, infants aged 6-12 months were evaluated using the PEDS combined. A study population of 34 infants was selected for sampling. Using a confidence level of 95%, a margin error of 5% and a response distribution of 50%, a minimum sample size of 32 infants was recommended for the study.

2.9.3 Response rate

Response rates vary with the subject studied and the methodology used. The response rate can be increased by contacting telephonically non-respondents, and/ or leaving voicemail messages by cell phone as reminders. In surveys published in medical journals, a 60% response rate is classified as an acceptable response rate. Published physicians' surveys have a mean response rate of 54% (Asch, Jedrziwski et al. 1997).

2.10 ETHICS

- 1 Questionnaires and feedbacks were anonymous and confidential, and the content was only known by the researcher.
- 2 Parents volunteered to participate in the study and had the right to withdraw their consent at any point of time and there was no compromise of the service given to patients at the neurodevelopment clinic.
- 3 Written permission was obtained from the hospital Chief Executive Officer (CEO) to conduct the research and collect the files from the hospital medical records department.

- 4 Ethical clearance for the study was obtained from the human research ethics committee of the University of Wits. Clearance certificate M120678.

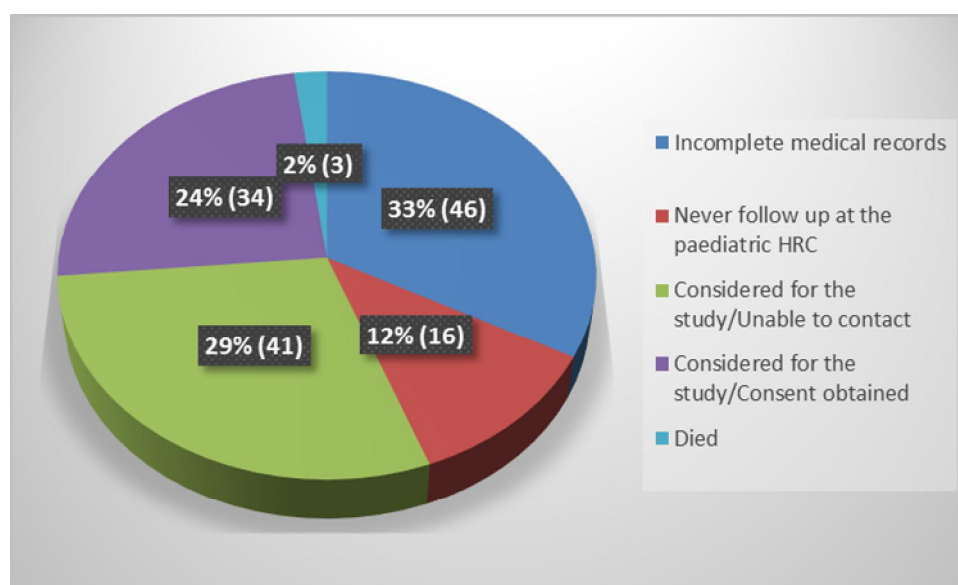
3 RESULTS

3.1 DESCRIPTIVE ANALYSIS

3.1.1 STUDY SAMPLE

At the start of the collection of data, 140 infants were considered for the study following the review of hospital medical records. Of these, 46 infants had incomplete medical records, 16 infants never had a follow up at the paediatric HRC and 3 children had died. There were thus 75 infants considered for the study, of which 41 parents could not be contacted. So the final study sample consisted of 34 infants and their parents. (Figure 1)

Figure 1 Study sample



3.1.2 INFANTS AND PARENTS CHARACTERISTICS

The age of infants at the completion of the PEDS combined questionnaires ranged between 6-12 months. The review of the medical records revealed that all 34 infants considered for the study had followed up at HRC, and of these, 10 infants were discharged from follow up and 24 infants had appointment dates for follow up. All infants included in the study were admitted to the neonatal ward and were reviewed routinely by audio and

speech therapists (100%) before discharge from the hospital. The study population characteristics and variables are presented in the Table 2 below.

Table 2 Infants characteristics

		Total number	Percentage
Number of infants		34	100
Birth weight (Grams)	Mean	3161	
	Range	2500-4170	
Gestational age at birth (weeks)	Mean	39	
	Range	38-42	
Sex	Male	21	62
	Female	13	38
Reason for admission to neonatal ward	HIE 1	20	59
	HIE 2	10	29
	HIE 3	4	12
Length of stay in the neonatal ward (Days)	Mean	8.4	
	Range	2-26	
Review by OT and Audio-speech therapist in neonatal ward		34	100
Number of visit to the paediatric HRC per child	Mean	1.6	
	Range	1-3	
Number of infants discharged from the paediatric HRC		10	29

The age of parents at the completion of the PEDS combined and the demographic questionnaires ranged between 17 and 40 years. There were 34 parents who completed the questionnaires. Of these, 32 were female and 2 were male parents. Approximately 29 parents had only high school education level and 22 were unemployed or not formally employed. Of these, 12 parents depended on the social child grant for their living and 10 parents were self-employed. Lastly, the review of data shows that 23 infants lived in households of 1-2 children, while the remaining 11 infants lived in households of 3 or more children. (Table 3)

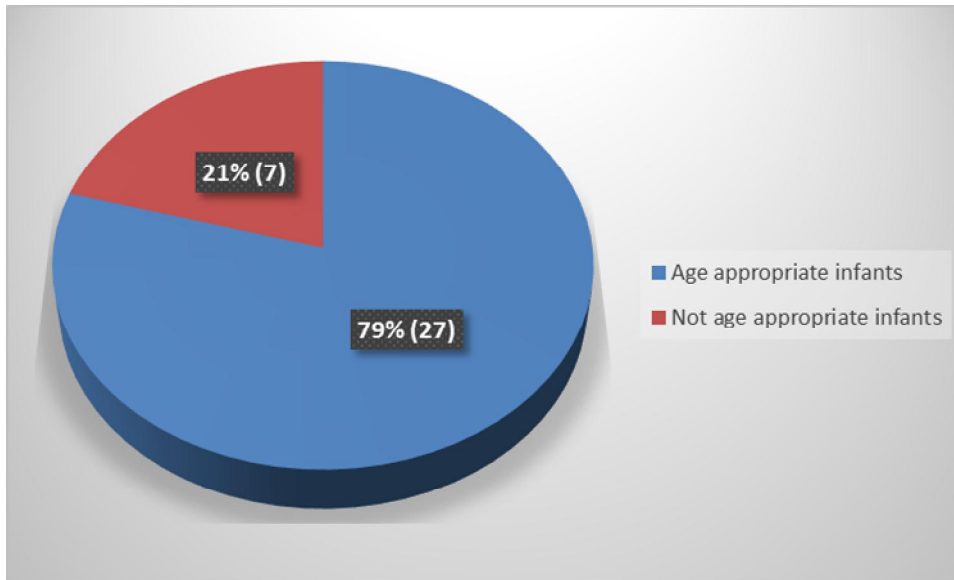
Table 3 Parents' demographic characteristics

		Total number	Percentage
Number of parents		34	100
Parent 's age (Years)	Mean	27.6	
	Range	17-40	
Male sex		2	6
Female sex		32	94
Married		12	35
Single		21	62
Separated		1	3
Education: primary		2	6
Education: High school		29	85
College/University		3	9
No additional caregiver		12	35
Additional caregiver		22	65
Number of children in household	1-2	23	68
	3 or more	11	32
Live in a house		11	32
Live in a shelter		7	21
Live in a Backroom		16	47
Formal income from employer		12	35.3
Child grant		12	35.3
Self employed		10	29.4

3.1.3 DEVELOPMENTAL CONCERNS: PEDS combined

Of 34 infants included in the study 27 (79%) infants were found to be age appropriate and 7 (21%) infants were classified as developmentally delayed and required further developmental assessment. (Figure 2)

Figure 2 PEDS combined: Parental concerns

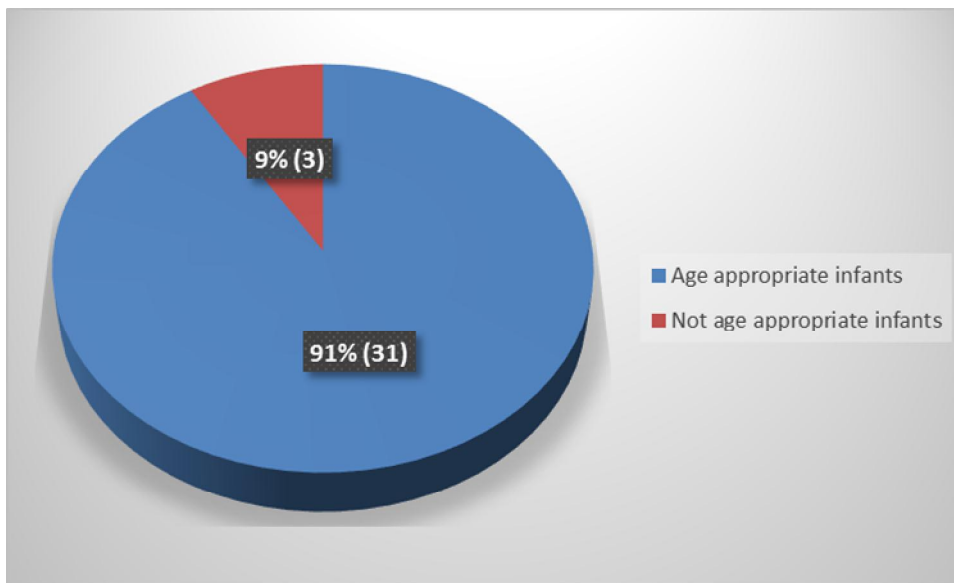


3.1.4 Routine professional assessment: review of infants medical records

3.1.4.1 Developmental outcomes

Thirty four medical records were reviewed with focus on the clinical assessment. It was found that 31 (91%) infants were developmentally age appropriate and 3 (9%) infants were developmentally delayed. (Figure 3)

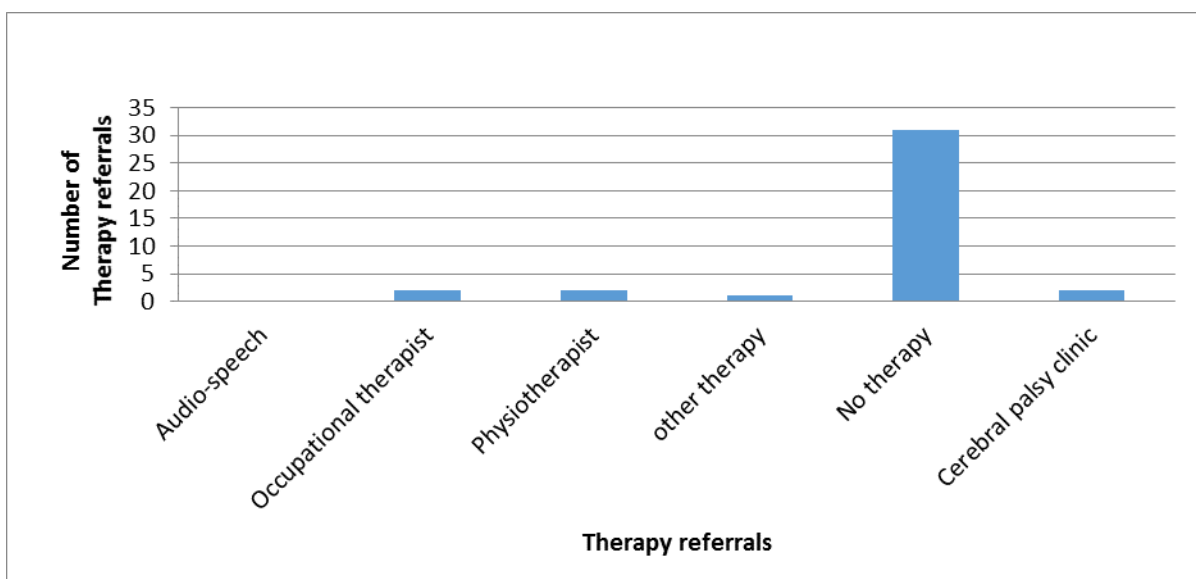
Figure 3 Review of medical records: developmental outcome



3.1.4.2 PHYSIOTHERAPY AND OCCUPATIONAL THERAPIST REFERRAL

Of the 34 infants who followed up at the HRC, 31 infants had no therapy referral. However, of the remaining three infants, there were two physiotherapy referrals; two occupational therapy referrals and two infants' referrals to the cerebral palsy (CP) clinic. Lastly, one of the infants referred to the CP clinic was also referred for other therapy and was assessed by ophthalmologist for cortical blindness. (Figure 4)

Figure 4 Referral for Therapy after follow up at the HRC



3.1.5 CONCERNS PER DEVELOPMENTAL DOMAIN

3.1.5.1 PEDS combined

Table 4 below summarizes parental domains of developmental concerns and interpretation of PEDS combined outcomes in the current study. The administration of the PEDS combined was followed by the scoring and the interpretation of parental concerns. Diversified referral pathways were used as needed to improve the infant's developmental status. The PEDS combined has two steps of screening that involve the use of the PEDS questionnaire and the PEDS: DM questionnaire.

The administration and scoring of the PEDS questionnaire revealed that nine parents had diversified developmental concerns. Overall, GM was the most frequently identified domain with seven concerns, followed by FM with six concerns. Four concerns were identified in the other/health developmental domain. Self-help domains recorded three concerns. Lastly, the PEDS identified one expressive language concern and one behavioural concern.

The administration of the PEDS: DM after completing and scoring PEDS forms revealed varied developmental concerns from seven parents. Of these, six infants had GM milestones unmet, five infants had self- help developmental concerns and three infants had FM milestones concerns. Lastly, two infants had SE milestones unmet and one infant had expressive language concern following scoring and interpretation of PEDS: DM responses. (Table 6)

Table 4 PEDS combined: summary of domains of developmental concerns and scores

Infants and age at test	PEDS		PEDS:DM	
Infant 1, Age: 8 months	Non-predictive concerns	FM, GM	Milestones unmet	GM, self help
	Predictive concerns	None	Milestones met	FM, SE, EL, RL
	Path	C-2 (Risk for SE, behavioural and mental health problems)		
Infant 2, Age: 7 months	Non-predictive concerns	FM, GM, Self help	Milestones unmet	FM, GM, EL, Self help
	Predictive concerns	EL, Other/health	Milestones met	RL, SE
	Path	A-2 (High risk for developmental, behavioural problems)		
Infant 3, Age: 12 months	Non-predictive concerns	FM, GM	Milestones unmet	GM
	Predictive concerns	None	Milestones met	FM, RL, EL, SE, Self help
	Path	C-2 (Risk for SE, behavioural and mental health problems)		
Infant 4, Age: 11 months	Non-predictive concerns	GM	Milestones unmet	None
	Predictive concerns	None	Milestones met	FM, GM, EL, RL, SE, Self help
	Path	C-2 (Risk for SE, behavioural and mental health problems)		
Infant 5, Age: 6 months	Non-predictive concerns	None	Milestones unmet	None
	Predictive concerns	Other/ health	Milestones met	FM, GM, EL, RL, SE, Self help
	Path	B-1 (Moderate risk for developmental problems, questionable health status)		
Infant 6, Age: 9 months	Non-predictive concerns	GM	Milestones unmet	GM, self help
	Predictive concerns	Other/ health	Milestones met	FM, EL, RL, SE
	Path	B-1 (Moderate risk for developmental problems, questionable health status)		
Infant 7, Age 8 months	Non-predictive concerns	FM, Behaviour	Milestones unmet	SE
	Predictive concerns	None	Milestones met	FM, RL, EL, GM, Self help
	Path	C-2 (Risk for SE, behavioural and mental health problems)		
Infant 8, Age: 12 months	Non-predictive concerns	FM, GM, Self help	Milestones unmet	FM, GM, Self help
	Predictive concerns	None	Milestones met	EL, RL, SE
	Path	C-2 (Risk for SE, behavioural and mental health problems)		
Infant 9, Age 11 months	Non-predictive concerns	FM, GM, Self help	Milestones unmet	FM, GM, SE, Self help
	Predictive concerns	Other/ health	Milestones met	RL, EL
	Path	B-1 (Moderate risk for developmental problems, questionable health status)		

3.1.5.2 Review of medical records: Neurological and developmental domains

The medical records of infants who had developmental concerns following the administration and scoring of the PEDS combined were reviewed. Diversified developmental concerns were identified. Of these, GM was the most frequently identified domains with 3 concerns, followed by FM, self-help and other/health domains recording 2 concerns each. Lastly, no other developmental domains were identified from the review of medical record. (Table 5) Two infants had cerebral palsy; and one infant had both cerebral palsy and cortical blindness.

Table 5 Number of concerns per developmental domains (Medical record review)

Infants and age at test	Clinical assessment outcomes	
Infant 1, Age: 8 months	Developmental concerns	None
Infant 2, Age 7 months	Developmental concerns	GM
Infant 3, Age 12 months	Developmental concerns	GM, FM, Self-help
Infant 4, Age: 11 months	Developmental concerns	None
Infant 5, Age 6 months	Developmental concerns	Other/Health
Infant 6, Age: 9 months	Developmental concerns	None
Infants 7, Age: 8 months	Developmental concerns	None
Infant 8, Age 12 months	Developmental concerns	None
Infant 9, Age: 11 months	Developmental concerns	GM, FM, Self-help, Other/Health

3.1.5.3 Developmental outcomes: Comparison of PEDS combined and professional assessment

The review of the data recorded in table 6 shows that the GM domain of development was the most commonly identified concern by both the PEDS combined and the routine clinical assessment. The PEDS combined identified six unmet GM milestones; and the professional assessment identified only three GM concerns in infants. The PEDS combined also identified a higher number of infants with FM, self-help, SE, and communications concerns. Overall, the review of medical records revealed that professional assessment identified the least number of concerns in all domains, except for other/ health domain of development.

Table 6 Developmental outcomes: comparison of PEDS combined and professional assessment

Infants and age at test	Developmental concerns: PEDS combined	Developmental concerns: Routine assessment professional
Infant 1, Age: 8 months	GM, Self help	None
Infant 2, Age: 7 months	FM, GM, EL, Self help	GM
Infant 3, Age: 12 months	GM	GM, FM, Self-help
Infant 5, Age: 6 months	None	Other/ Health
Infant 6, Age: 9 months	GM, Self help	None
Infant 7, Age: 8 months	SE	None
Infant 8, Age: 12 months	FM, GM, Self help	None
Infant 9, Age: 11 months	FM, GM, SE, Self help	FM, GM, Self-help, Other/ Health

3.2 COMPARATIVE ANALYSIS

3.2.1 Comparison of PEDS combined and routine professional assessment: parental concerns

The use of the Kappa agreement test showed a difference in developmental outcomes between the PEDS combined and the routine professional assessment. The inter-rater agreement between the two methods was moderate ($K = 0.544$, 95% CI 0.170 to 0.917). The observed agreement between the two methods was 88.24%, whilst the agreement expected by chance was 74.22%. The actual inter-rater agreement was greater than the agreement expected by chance. The difference meant that the routine professional assessment was more likely to classify an infant as age appropriate, whilst the PEDS combined was more likely to classify the same infant as needing further developmental assessment.

3.2.2 Comparison of PEDS combined and routine professional assessment: Domains of developmental

For the GM domain, the strength of agreement was good between the PEDS combined and the routine professional assessment ($K = 0.622$, 95%CI 0.244 to 1). For the FM domain, the agreement was also found to be good ($K = 0.785$, 95% CI 0.379 to 1); with the PEDS more likely to elicit GM and FM developmental concerns than routine professional assessment. In the self-help domain, the agreement between the PEDS combined and the routine professional assessment was moderate ($K = 0.532$; 95% CI 0.085 to 0.979), with the PEDS combined more likely to identify an infant as not age appropriate. On the contrary, the routine professional assessment was more likely to identify an infant with the other/health domain concern, and the resulting strength of agreement with PEDS combined was poor ($K < 0.20$). Lastly, the PEDS combined was more likely to elicit SE and communication unmet milestones than routine professional assessment; and the agreement between the two methods was poor ($K < 0.20$). Overall, the PEDS combined was more likely to elicit developmental milestone concerns.

4 DISCUSSION

4.1 IDENTIFICATION OF DEVELOPMENTAL CONCERNS

The early identification of infants with developmental delay is important so that appropriate interventions can be started. This study showed that parental assessment is a reliable way of early identification of developmental concerns in infants. The PEDS combined identified 21% of infants with developmental concerns; whereas, the routine professional assessment only identified 9% of infants as developmentally age inappropriate. The resulting kappa inter rater agreement between the two methods was moderate ($K = 0.544$). The observed agreement between the two methods was 88.24%, whilst the agreement expected by chance was 74.22%. This difference meant that subjective developmental impressions based on routine clinical assessments may have missed a significant proportion of children with developmental delays. These findings confirm the results of a number of studies which have shown the under detection of developmental delays when health care providers do not use standardised screening methods (Shevell, Majnemer et al. 2001, Klein and McCarthy 2009). The early identification developmental delay is a multi-step process that involves the use of screening tests, health surveillance and the routine clinical assessments. Gathering information from parents is undoubtedly cost-effective and the most important aspect of a clinical evaluation of development; and the sensitivity and specificity is 70-80% as good as standardised screening methods for detecting developmental concerns. However, if the questionnaire is poorly administered, up to 40% of parents may not mention concerns even when their child has developmental issues (Sharma 2011).

4.2 DOMAINS OF DEVELOPMENT: PEDS COMBINED AND ROUTINE PROFESSIONAL ASSESSMENT OUTCOMES

The assessment and interpretation of domains of developmental is essential to illustrate predictive and non-predictive developmental concerns at different age groups. Information gathered from parents is crucial for eliciting developmental milestone concerns and the implementation of focused early intervention programs. Findings in the current study showed that the PEDS combined was more likely to elicit most unmet developmental milestones such as GM ($K = 0.622$), FM ($K = 0.785$), self-help ($K = 0.532$), SE ($K < 0.20$) and communication ($K < 0.20$) in infants, though the other/health domain ($K < 0.20$) of development was more likely to be identified by the routine professional assessment. The

study found variable degrees of inter-rater Kappa agreement between the two methods. The routine professional assessment presented a risk of under-detection of developmental issues and might have resulted in the lack of referral of infants for early intervention.

A study done by the Department of physical medicine and rehabilitation at the Taipei Medical School and hospital found that, parents' concerns about speech, motor and behavioural domains had a high sensitivity (77-89%); and comparatively, cognitive concerns had lower sensitivity (15-36%) in the assessment of 101 infants (Chen, Lee et al. 2004).

Infants' developmental concerns are often delicate and difficult to differentiate from normality. Frances Page Glascoe, in one of her articles, illustrated these challenges by saying that a child who has attention deficit or behaviour developmental concerns may be obedient and focused during a short office assessment. Another example is that a child with disability may talk, but may not talk well (Glascoe 2000). Therefore, caution should be exercised while eliciting and assessing developmental concerns in an infant. The development of a child is dynamic and should be considered as a moving target with changing nature of predictive and non-predictive concerns at different age groups. For example, from 6-12 months of age, the receptive language, FM, GM, behaviour, self-help and other/health domains are regarded as non-predictive concerns. It may be very difficult to clearly elicit language impairment in an infant until the use of various combination of words fails to emerge or emerges only in an attenuated state at the next age level. The language difficulty could simply be due to an undetected hearing impairment. One other example is that of a parent with developmental concern following the screening of an infant with PEDS combined. It is possible for the same parent not to have the same developmental concern when the child is 2 or 3 years old (Glascoe 2000). It is, therefore necessary to use screening tests, especially those involving parents, together with routine professional assessment to monitor children development and progress over time. The screening should be considered not only for children with developmental concerns, but also for infants developing normally

4.3 RESPONSE RATE

Response rates vary according to the subject studied and techniques used (Asch, Jedrziwski et al. 1997). The response rate to questionnaires in the current study was 100% and greater than 60%. The latter is the acceptable response rate in surveys published in medical journals (Asch, Jedrziwski et al. 1997).

4.4 DEMOGRAPHIC CHARACTERISTICS

The demographic data was collected for this study. But the question is whether the information provided by parents is influenced by their socio-demographic characteristics. Research shows that almost all parents, if presented with standardised questionnaires, can give accurate information about their child, regardless of differences in socio-demographic status and well-being. One of the reasons is that, parents usually derive their responses by comparing their children with other children. Nevertheless, parents who have limited education often have limited literacy, and they may respond randomly to questions or omit some items. However, parents with poor literacy had someone go through the questions with them to help with the understanding and completion of the screening questionnaire. The PEDS combined has no socio-demographic restriction, it is recommended for use in infants from both high and low socio-economic groups (Glascoe 2000). Even though the majority of respondents, in the current study, were from lower socio-economic status, had low education levels and were younger (mean age 27.7 years), the influence of these findings could not be extrapolated onto the comparison of the routine professional assessment and the PEDS combined. The sample size is too small to be able to analyse the effect of socio-economic effects on developmental assessment.

4.5 SCREENING PROCEDURES

Developmental screening of infants is a cornerstone of early intervention. Early intervention programs provide enriching developmental settings for children, train parents and improve their understanding infant development, make provision for continuous positive redirection and focus on skills building. Research shows that early childhood interventions produce important economic, academic, and social benefits in the short-term and long-term. These children are more likely to complete their studies, get employed and

maintain jobs, be independent and avoid teenage pregnancies and criminality, and have improved health related behaviour (Nores et al. 2005, Nores 2010). Early intervention programs clearly offer benefits that depend on early screening and detection (Glascoe 2000). In the current study, it was found that most physicians rely on the clinical judgement alone for decision making and not on screening procedures to detect infants with developmental delays. Fewer than 30% of children with mental retardation, communication disabilities, learning difficulties, and developmental delays are detected by clinical judgement alone (Glascoe 2000). These findings reinforce the necessity for the use of screening procedures. The most effective tests used in primary health care are those that are based on information from parents. Although 20% to 30% of children will be over-referred for in-depth developmental assessment, these children will still require appropriate care from clinicians and their parents will receive developmental training and education and will be made vigilant to detect emerging disabilities (Glascoe 2000).

5 LIMITATIONS

The child developmental trajectory should be assessed at different age groups and the PEDS combined is a validated screening test used for children aged 0 to 8 years. However, in this study, each infant only received one PEDS combined Screening at the age 6-12 months. Screening of these infants at different points in time would have been useful not only in the comparison of PEDS combined and routine professional assessment, but also in identifying infants with developmental delays.

The current study was conducted at a public health care hospital in South Africa. There were difficulties locating some data in the patients' medical records due to missing files and/ or illegible notes. The sample size of this study is small and is not be representative of the South African population at large. A study looking at the overall South African health care system would have added more value to the assessment of the use of screening tools relying on parental information both in private and public health care sectors. Furthermore, an overall South African study would be important in comparing South Africa developmental medicine to that of other countries. Lastly, it is impossible to ascertain whether non-respondents have introduced bias in this study. It is also impossible to know whether non-respondents would have answered the PEDS combined questionnaires differently from the responders.

6 RECOMMENDATIONS

It is important for health professionals to use cost effective screening tools that rely on information from parents in child health. This weakness in the area of child developmental assessment by health professionals can be improved. There is need for continuous professional development programs that raise awareness and give training on the use of both the routine professional assessment and parent developmental screening tools in developmental medicine and in early intervention programs.

The child developmental concerns should be looked at in the context of developmental trajectories at different age groups. The parental developmental concerns require the health professional to do in-depth developmental assessment of the child and further follow ups over time.

It will be important to reinforce the use of parental developmental screening programs, such as PEDS combined, in public and private health care institutions in South Africa to improve developmental outcomes in child health. Furthermore, more large scale studies are needed to study the impact of the use of these developmental screening programs in South African hospitals. Further investigations are also needed to study the costs and practical modalities of using parents' administered screening tools in South Africa.

Lastly, it is essential for future researchers not only to address gaps in developmental medicine, but to also help translate their findings into public health policies that would positively impact the lives of children in South Africa and other countries.

7 CONCLUSION

This study highlighted the importance of gathering information from parents as the most important aspect of a clinical evaluation in the area of child development. The inter-rater comparison between the PEDS combined and the routine professional assessment identified potential gaps in the practice of eliciting developmental concerns in child health. The discordance meant that the PEDS combined was more likely to identify developmental concerns than routine professional assessment. The routine professional assessment, used in isolation, presented a risk of under-detection of developmental issues and could

result in lack of referral of infants for in-depth developmental assessment and early intervention.

The present study also looked at socio-demographic characteristics of parents who provided developmental information of infants. The influence of these findings could not be extrapolated onto the way parents interpret their children developmental milestones. Research shows that almost all parents, if presented with standardised questionnaires, can give accurate information about their child, regardless of differences socio-demographic status and well-being (Glascoe 2000).

8 APPENDIX

8.1 ETHICAL CLEARANCE



UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

R14/49 Dr Faustin M Kabasele

CLEARANCE CERTIFICATE

M120678

PROJECT

Comparison of Parents' Evaluation of Developmental Status and Professional Assessment for Early Detection of Developmental Disorders

in Infants Born at Term with Birth Asphyxia at Tembisa Hospital at Tembisa Hospital

INVESTIGATORS

Dr Faustin M Kabasele.

DEPARTMENT

Department of Paediatrics & Child Health

DATE CONSIDERED

29/06/2012

DECISION OF THE COMMITTEE*


Approved unconditionally

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE

13/08/2012

CHAIRPERSON


(Professor PE Cleaton-Jones)

*Guidelines for written 'informed consent' attached where applicable

cc: Supervisor : Prof D Ballot

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10004, 10th Floor, Senate House, University.

I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES...

8.2 PEDS PACK

8.2.1 QUESTIONNAIRE

PEDS RESPONSE FORM

Child's Name _____ Parent's Name _____

Child's Birthday _____ Child's Age _____ Today's Date _____

Please list any concerns about your child's learning, development, and behavior.

Do you have any concerns about how your child talks and makes speech sounds?

Circle one: No Yes A little COMMENTS:

Do you have any concerns about how your child understands what you say?

Circle one: No Yes A little COMMENTS:

Do you have any concerns about how your child uses his or her hands and fingers to do things?

Circle one: No Yes A little COMMENTS:

Do you have any concerns about how your child uses his or her arms and legs?

Circle one: No Yes A little COMMENTS:

Do you have any concerns about how your child behaves?

Circle one: No Yes A little COMMENTS:

Do you have any concerns about how your child gets along with others?

Circle one: No Yes A little COMMENTS:

Do you have any concerns about how your child is learning to do things for himself/herself?

Circle one: No Yes A little COMMENTS:

Do you have any concerns about how your child is learning preschool or school skills?

Circle one: No Yes A little COMMENTS:

Please list any other concerns.

8.2.2 SCORE SHEET

PEDS Score Form												
Find appropriate column for the child's age. Place a checkmark in the appropriate box to show each concern on the PEDS Response form. See Brief Scoring Guide for details on categorizing concerns. Shaded boxes are predictive concerns. Unshaded boxes are non-predictive concerns.												
Child's age:	0-3 m	4-5	6-11	12-14	15-17	18-23	2	3	4-4-5	4-6-5-11	6-7	7-8
Global/Cognitive	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Expressive Language and Articulation	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Receptive Language	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Fine-Motor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Gross Motor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Behavior	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social-emotional	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Self-help	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
School	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Other	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Count the number of checks in the small shaded boxes and place the total in the large shaded box below.												
<input checked="" type="checkbox"/> <input checked="" type="checkbox"/> <input checked="" type="checkbox"/> <input checked="" type="checkbox"/> <input checked="" type="checkbox"/> <input checked="" type="checkbox"/> <input checked="" type="checkbox"/> <input checked="" type="checkbox"/> <input checked="" type="checkbox"/> <input checked="" type="checkbox"/> <input checked="" type="checkbox"/> <input checked="" type="checkbox"/>												
If the number shown in the large shaded box is 2 or more, follow Path A on PEDS Interpretation Form. If the number shown is exactly 1, follow Path B. If the number shown is 0, count the number of small unshaded boxes and place the total in the large unshaded box below.												
<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>												
If the number shown in the large unshaded box is 1 or more, follow Path C. If the number 0 is shown, consider Path D if relevant. Otherwise, follow Path E.												

8.2.3 EXAMPLE OF PEDS: DM Questions - TEST FORM D

Can your baby poke at things with just his or her first finger?	No A Little Yes
When you say your baby's name, does he or she stop and look at you?	No Sometimes Most of the time
How many different sounds such as "muh", "bah", "duh", or "guh" does your baby say?	None 1 2 or more
Can your baby get around on hands and knees or by scooting on his or her bottom?	No Sometimes Yes
Does your baby try to get to toys that are out of reach?	No A Little Yes
Does your baby like to play peek-a-boo?	No/Never Tried A Little Yes

8.3 CAREGIVER DEMOGRAPHIC SCREEN FORMS

Parents with poor literacy will be offered assistance with filling out the questionnaire or by administering the screening as an oral interview.

Mark an X in the appropriate coloured row for EACH point

Gender	Male	
	Female	
Marital status	Married	
	Single	
	Separated	
	Widow/Widower	
	Divorced	
Level of education attended	Primary	
	High school	
	College/university	

Circle either the word or the letter for your answer as appropriate and write answers where space is provided:

How old are you? _____ Years old
Current monthly income, including public assistance. R_____
Are you the child's A. Mother B. Father C. Grandparent D. Foster parent E. Relative F. Other
Besides you, does anyone else take care of the child? Yes No If yes, Who? _____
Number of children in the household A. 1-2 B. >2 Where do you live with your child now? A. House or apartment B. Shelter C. Other_____
What are you currently doing? A. Working full-time for pay B. Working part-time for pay C. Not working, but looking for a job C. Not working, but not looking for a job D. Personal/Family business E. Retired F. Unpaid work

8.4 PROFESSIONAL ASSESSMENT FORM (DATA CAPTURE SHEET)

Baby's name:

Date:

Date of last appointment:

Mark an X in the appropriate column for EACH point. (1- 9)

Make any relevant comments underneath each point

	Delayed - Refer for in depth assessment / intervention	Concerned :- monitor carefully	Not concerned at this time
1. Global/cognitive			
Comments:			
2.Expressive language			
Comments:			
3.Receptive language			
Comments:			
4. Fine motor			
Comments:			
5. Gross motor			
Comments:			
6. Behaviour			
Comments:			
7.Social- emotional			
Comments:			
8. Self help			
Comments:			
9. Other			
Comments:			

9 REFERENCE

- Aly, Z., F. Taj and S. Ibrahim (2010). "Missed opportunities in surveillance and screening systems to detect developmental delay: A developing country perspective." Brain Dev **32**(2): 90-97.
- Asch, D. A., M. K. Jedrzewski and N. A. Christakis (1997). "Response rates to mail surveys published in medical journals." Journal of Clinical Epidemiology **50**(10): 1129-1136.
- Centre for Community Child Health and The Royal Children's Hospital (2011). "Monitoring Child Development: Parents Evaluation of Developmental Status". http://www.rch.org.au/ccch/resources_and_publications/Monitoring_Child_Development/#faq_peds.
- Chen, I. C., H. C. Lee, G. C. Yeh, C. H. Lai and S. C. Chen (2004). "The relationship between parental concerns and professional assessment in developmental delay in infants and children--a hospital-based study." J Chin Med Assoc **67**(5): 239-244.
- de Haan, M., J. S. Wyatt, S. Roth, F. Vargha-Khadem, D. Gadian and M. Mishkin (2006). "Brain and cognitive-behavioural development after asphyxia at term birth." Dev Sci **9**(4): 350-358.
- Geonames (2011). "Tembisa Online." <http://www.geonames.org/949880/tembisa.htm>.
- Glascoe, F. P. (1997). "Parents' Concerns About Children's Development: Prescreening Technique or Screening Test?" Pediatrics **99**(4): 522-528.
- Glascoe, F. P. (1999). "Using parents' concerns to detect and address developmental and behavioral problems." J Soc Pediatr Nurs **4**(1): 24-35.
- Glascoe, F. P. (2000). "Early Detection of Developmental and Behavioral Problems." Pediatrics in Review **21**(8): 9.
- Glascoe, F. P. (2011). "How to administer PEDS: Parents Evaluation of Developmental Status."
- Halloran, D. R., E. McClure, H. Chakraborty, E. Chomba, L. L. Wright and W. A. Carlo (2009). "Birth asphyxia survivors in a developing country." J Perinatol **29**(3): 243-249.
- Jones, J. G., T. Worthington, F. Hawks, S. O. Mercer, B. W. Jones and L. Woon (1998). "Ad Hoc conferences of hospital and community professionals in cases of hospitalized physically abused children." Child Abuse Negl **22**(1): 63-68.

- Klein, S. and D. McCarthy (2009). "North Carolina's ABCD program: using community care networks to improve the delivery of childhood developmental screening and referral to early intervention services." Issue Brief (Commonw Fund) **66**: 1-28.
- Kromberg, J., E. Zwane, P. Manga, A. Venter, E. Rosen and A. Christianson (2008). "Intellectual Disability in the Context of a South African Population." Journal of Policy and Practice in Intellectual Disabilities **5**(2): 89-95.
- Lindström, K., P. Lagerroos, C. Gillberg and E. Fernell (2006). "Teenage Outcome After Being Born at Term With Moderate Neonatal Encephalopathy." Pediatric Neurology **35**(4): 268-274.
- Maulik, P. K. and G. L. Darmstadt (2007). "Childhood Disability in Low- and Middle-Income Countries: Overview of Screening, Prevention, Services, Legislation, and Epidemiology." Pediatrics **120**(Supplement 1): S1-S55.
- Motala, C., A. Davidson, A. Figaji and M. e. Levin (2010). "Handbook of Paediatrics."
- Mwakyusa, S. D., K. P. Manji and A. W. Massawe (2009). "The Hypoxic Ischaemic Encephalopathy Score in Predicting Neurodevelopmental Outcomes Among Infants with Birth Asphyxia at the Muhimbili National Hospital, Dar-es-Salaam, Tanzania." Journal of Tropical Pediatrics **55**(1): 8-14.
- Nores, M. (2010). The Economics of Early Childhood Interventions. International Encyclopedia of Education (Third Edition). P. P. B. McGaw. Oxford, Elsevier: 450-455.
- Nores, M., Belfield, C. R., Barnett, W. S., and Schweinhart, L. (2005). Updating the economic impacts of the high/scope Perry preschool program. Educational Evaluation and Policy Analysis **27**(3), 245.
- Pin, T. W., B. Eldridge and M. P. Galea (2009). "A review of developmental outcomes of term infants with post-asphyxia neonatal encephalopathy." European Journal of Paediatric Neurology **13**(3): 224-234.
- Shah, P. M. (1991). "Prevention of mental handicaps in children in primary health care." Bull World Health Organ **69**(6): 779-789.
- Sharma, A. (2011). "Developmental examination: birth to 5 years." Arch Dis Child Educ Pract Ed **96**(5): 162-175.
- Shevell, M. I., A. Majnemer, P. Rosenbaum and M. Abrahamowicz (2001). "Profile of referrals for early childhood developmental delay to ambulatory subspecialty clinics." J Child Neurol **16**(9): 645-650.

- Silva, M. L. (2010). "A comparison of objective, standardised parent- administered questionnaires to that of subjective screening practices for the early detection of developmental delay in at- risk infants." WIReDSpace.
- Statistics, S. A. (2014). "The population of all main places in the Ekurhuleni Metropolitan Municipality." http://beta2.statssa.gov.za/?page_id=1021&id=ekurhuleni-municipality.
- Swanepoel, D. W. (2009). "Early detection of infant hearing loss in South Africa." SAMJ: South African Medical Journal **99**(3): 158-159.
- Theeranate, K. and S. Chuengchitraks (2005). "Parent's Evaluation of Developmental Status (PEDS) detects developmental problems compared to Denver II." J Med Assoc Thai **88 Suppl 3**: S188-192.
- Thilo, E. H. and A. A. Rosenberg (2012). Chapter 2. The Newborn Infant. CURRENT Diagnosis & Treatment: Pediatrics, 21e. W. W. Hay, M. J. Levin, R. R. Deterding, M. J. Abzug and J. M. Sondheimer. New York, NY, The McGraw-Hill Companies.
- Velaphi, S. and R. Pattinson (2007). "Avoidable factors and causes of neonatal deaths from perinatal asphyxia-hypoxia in South Africa: national perinatal survey." Ann Trop Paediatr **27**(2): 99-106.